

# Missouri Title V Facts:

## Children & Youth with Special Health Care Needs



### Background

The term “children and youth with special health care needs” refers to a diverse population of young individuals with chronic conditions, medical complexity, and/or emotional or behavioral conditions. These conditions may reduce with age, be addressed through medical or behavioral interventions, or may represent lifelong medical impact for the child and his or her family. These children often benefit from services and supports beyond that required by the average child. These supports are not exclusive to the health care system, but may include associated systems such as mental health, transportation assistance, additional medical supplies, and more. It is estimated that approximately 21% of Missouri youth aged 0-17 have special health care needs, representing nearly 300,000 individuals.<sup>1</sup> Timely identification of special health needs, as through regular health care visits or developmental screening, has the potential to significantly impact outcomes for members of this population.

The federal Title V Maternal and Child Health Block Grant program focuses on two major roles for programs addressing the needs of CYSHCN: supporting medical home development and utilization (including issues surrounding access to care), and supporting systems to transition CYSHCN to adult care.



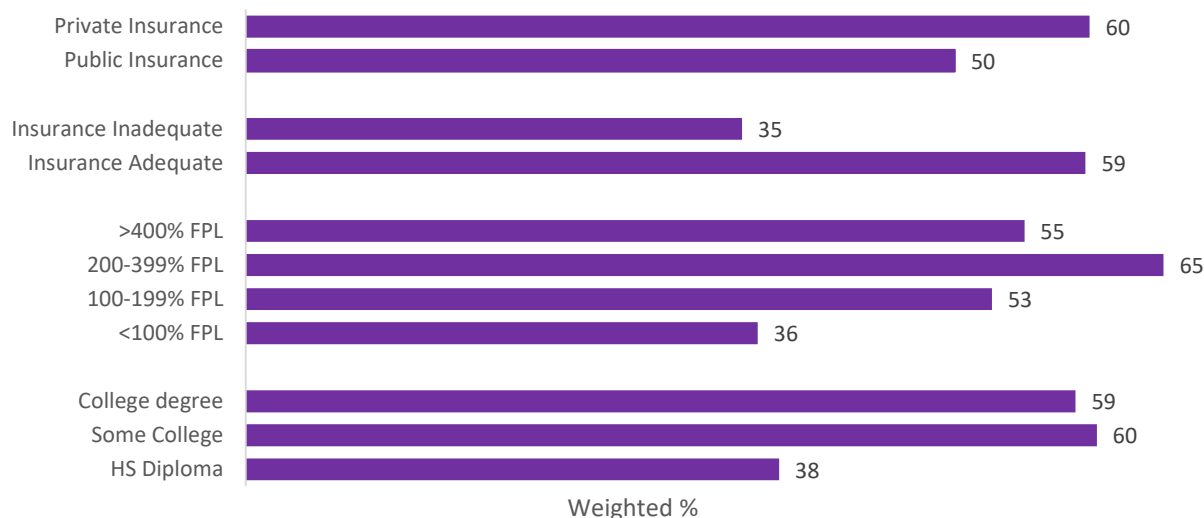
### Medical Home

The American Academy of Pediatrics (AAP) specifies that a medical home includes seven essential features: it is accessible, family-centered, continuous, comprehensive, coordinated, compassionate and culturally effective. A medical home has many identified benefits for children with and without special health needs. Medical homes can improve identification of disabilities and developmental issues, and they encourage care coordination both vertically and horizontally.<sup>2</sup> The impact of medical homes has been most extensively studied in young children, but adolescents can benefit as well, particularly from coordination around behavioral and mental health.<sup>3</sup>

In 2017-2018, 51% of Missouri youth with special health care needs received care through a system that met medical home criteria, a rate consistent with that of non-CYSHCN. However, among CYSHCN, those with more complex health needs were *less* likely to have a medical home (41%) than those with less complex health needs (67%).<sup>4</sup> Rates of medical home adequacy decline as children age, from 62% among children younger than age 6, to 41% among adolescents 12-17.<sup>1</sup>

Medical home access for CYSHCN is impacted by the same social determinants that affect access to care in general, including parental income, education and insurance adequacy. CYSHCN with household incomes below 100% of the federal poverty line (FPL) received care that met medical home criteria only 36% of the time, compared to 65% among those with incomes 200%-399% FPL. Children who were continuously and adequately insured were nearly twice as likely to have a medical home than those who were not.<sup>1</sup> A survey of Family Partnership Retreat participant families indicated that families in rural and non-rural counties had approximately equal likelihoods of having a medical home for their child (58% in rural counties; 59% in urban and suburban counties), but families living in rural counties were 15% more likely to receive explicit assistance from their medical home in coordinating care for their child’s special health needs.

**Figure 1. Medical Home by Select Socioeconomic Determinants**

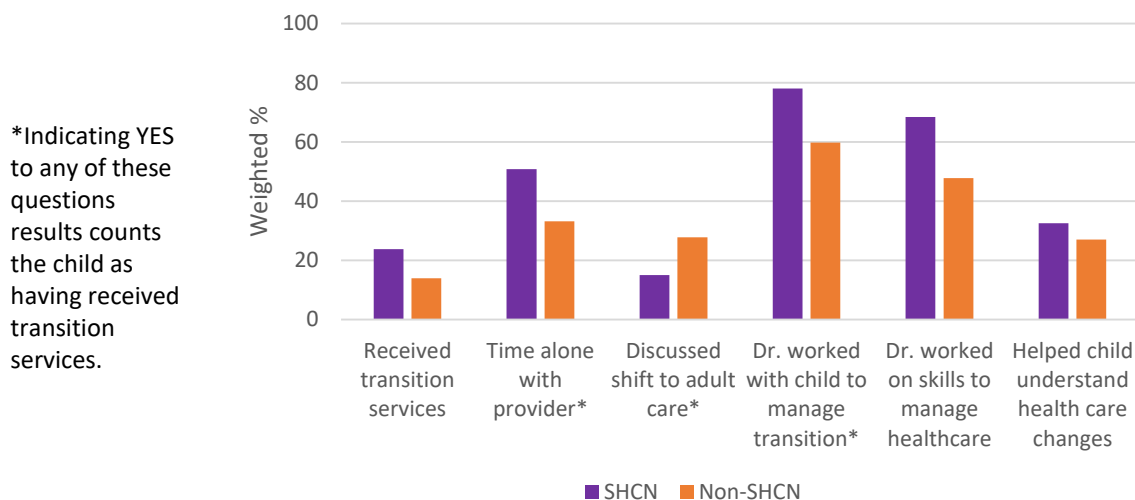


## Transition to Adult Care

Health care transition is the process of moving youth from pediatric to adult-centered health care. Successful transition should equip young adults with or without special health needs to manage their own health care, ensure access to necessary preventive care and specialty care, improve health literacy, and secure continuity of required services. This period is particularly important for CYSHCN, who may experience greater medical complexity, enhancing the need for increased coordination of health services to meet their medical needs.

The National Survey of Children's Health measures health care transition of children aged 12-17 years primarily through three components, asked of the parents: 1) Whether a doctor spoke with the child privately during the most recent preventive checkup or well-child visit; 2) A doctor worked actively with the child to gain skills to manage their own health care; 3) that a discussion about health care transition occurred if it was required. In 2017-2018, 24% of adolescents with special health care needs received transition services, compared to 14% of non-SHCN adolescents.<sup>1</sup>

**Figure 2. Components of Transition to Adult Care, SHCN and Non-SHCN Adolescents**



## Additional Services

Barriers to accessing and receiving health care can be influenced by race, socioeconomic status, educational attainment of parents or caregivers, geographic location, and other factors. Beyond differences in the availability of preventive, generalist, and specialist care, CYSHCN that live in rural areas experience barriers to accessing additional services such as respite care, home health services, and special education. 20% of Missouri CYSHCN are receiving special education or early intervention services, compared to 2% of the non-SHCN population.<sup>1</sup> Focus groups feedback from parents of CYSHCN indicated that parents in rural areas felt frustrated by limited availability of respite care and home health assistance, particularly for medically complex children.

*“The issue is where we live, the [home health] care is technically available but the nurses don’t want to come at times when we need them, like at night, because they only want to work the nine-to-five hours, when we don’t need them because [our child] is at school. And they don’t want to work with the kids who are hard to work with, who need them most. And[...] they can be choosy because they’re the only ones there [providing services].”*

## What is Being Done?

CYSHCN Program: The Children and Youth With Special Health Care Needs Program focuses on timely identification and care coordination for children with complex health needs who meet certain medical eligibility guidelines. This program also provides limited funding for diagnostic and treatment services for these children. <https://health.mo.gov/living/families/shcn/>

CYSHCN Family Partnership Program: The Family Partnership program serves as support and information resource for families of CYSHCN. The Family Partnership employs four Family Partners, who are parents of children with special health care needs, who provide peer support and referral assistance to family members. Two additional Family Partners specifically serve families of children who are deaf or hard of hearing (funded by the Health Resources and Services Administration Universal Newborn Hearing Screening and Intervention Program grant). The Family Partnership program also sponsors networking events for families of CHSHCN, including the annual Family Partnership Retreat. <https://health.mo.gov/living/families/shcn/familypartnership>

SchoolNurseLink: A website linking school nurses to MO HealthNet resources to assist with case management for students with chronic conditions, and provides guidance to school nurses in facilitating health insurance enrollment for all students, including those with SHCN. <http://www.schoolnurselink.com/>

Missouri Milestones Matter: A partnership between DHSS, and national and community partners, this effort seeks to embed developmental monitoring of young children more broadly into childcare settings using CDC’s “Learn The Signs. Act Early” materials, which include checklists and tools to make developmental screening easier for parents and caregivers.

## References:

1. Child and Adolescent Health Measurement Initiative. 2017-2018 National Survey of Children's Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by Cooperative Agreement U59MC27866 from the U.S. Department of Health and Human Services, Health Resources and Services Administration's Maternal and Child Health Bureau (HRSA MCHB). [www.childhealthdata.org](http://www.childhealthdata.org). Accessed March 3, 2020.
2. Stille C, Turchi RM, Antonelli R, Cabana MD, Cheng TL, Laraque D, Perrin J, Academic Pediatric Association Task Force on Family-Centered Medical Home. 2010. The family-centered medical home: Specific considerations for child health research and policy. *Academic Pediatrics* 10(4):211-217.
3. Walker, I., McManus, M. A., & Fox, H. B. (2011). Medical home innovations: where do adolescents fit. Washington, DC: Natl Alliance Adv Adolesc Heal Rep, 7.
4. Child and Adolescent Health Measurement Initiative. 2017-2018 National Survey of Children's Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by Cooperative Agreement U59MC27866 from the U.S. Department of Health and Human Services, Health Resources and Services Administration's Maternal and Child Health Bureau (HRSA MCHB). [www.childhealthdata.org](http://www.childhealthdata.org). Accessed March 3, 2020.